

**TOWARD A SUSTAINABLE ENTITLEMENT FOR THE
DEVELOPMENTAL SERVICES SYSTEM:**

A REGIONAL CENTER PERSPECTIVE

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PURPOSE

Social and economic changes occurring since the passage of the Lanterman Act in 1969 have made it increasingly difficult for the state to ensure funding that is adequate to implement the entitlement defined in the Act. Given the repeated economic fluctuations in California over the last 20 years, it would seem unrealistic to expect the state to guarantee to fully fund an entitlement that is so broadly defined according to individual need and continually expanding due to innovations in services and rising consumer and family expectations. It is critical, then, to carefully examine the factors contributing to the tension between the entitlement and the state's resources, and consider possible changes to the Act that would clearly define an entitlement that is sustainable given the state's financial resources. That is what this paper is intended to do.

The first section of the paper provides a brief description of regional centers and the people they serve. This is followed by a history of the Lanterman Act and the regional center system, and a discussion of the evolution of the entitlement and how it is financed. (An expanded discussion of the history of the system is available in the publication, *The Ever Widening Circle of Inclusion*, available from Frank D. Lanterman Regional Center.) This section provides a context for the subsequent discussion in Part III exploring the changes in the service system, target population, and financing that have created a tension between an ever-expanding entitlement and increased competition for finite financial resources in the state. The focus in the discussion is on services purchased by regional centers for consumers and their families. It is these services that consume by far the largest proportion of the regional center budget, and it is with regard to these services that state budget shortfalls have been most keenly felt by consumers and families. The paper concludes with a series of recommendations for changes that would enable the state to more reliably predict the cost of the entitlement and enable regional centers to more effectively manage the funds they receive while better ensuring equity in the distribution of those funds.

The term equity as used in this document means two things. The first relates to fairness across regional centers. Consumers should be given access to the same level and types of services no matter which regional center is coordinating their services. The second referent of the term equity is fairness across consumers within a regional center. Consumers with similar needs receiving services from the same regional center should receive similar levels and types of services regardless of their or their family's ability to advocate on their behalf.

It is important to emphasize that the people involved in the development of this paper strongly support the vision of the Lanterman Act. Frank Lanterman, Jerome Waldie, their colleagues in the Legislature, and a large number of committed parents and professionals embraced the ideals of equality and justice for people with developmental disabilities. Because of their vision and commitment, California created a community-based system of services and supports for people with developmental disabilities that has become a model for the rest of the U.S. This system has

provided people with ever expanding opportunities to live independent, productive, and satisfying lives as active members of their communities.

It is possible to support the concept of an entitlement and, at the same time, support the establishment of standards defining how the entitlement should be managed, including reasonable expectations regarding a family's financial responsibility for their child with a developmental disability. The goal of this paper is to contribute to a constructive dialogue that, it is hoped, will result in changes to the system so the entitlement can be sustained for future generations of people with developmental disabilities and their families. Given the near certainty that the current dismal economic climate will continue for the next several years, it is critical at this time to consider all reasonable alternatives and put forward a comprehensive set of recommendations that, taken together, will provide for an entitlement program that is sustainable in the long term.

As the title indicates, this paper is written from a regional center perspective. Given their mandated role of system coordinator among people with developmental disabilities and their families, community service providers, generic agencies, and state and federal agencies, the regional centers have a unique vantage point to view the developmental services system. Regional centers serve children and adults across the lifespan with all qualifying conditions, from all ethnic and socio-economic groups, and from vastly different geographic areas of the state. They identify, coordinate, and monitor a broad range of services provided through networks of hundreds, and in some cases thousands, of individuals and organizations. While certainly not the only valid perspective, the views of the regional center should be given careful consideration during the development of policy affecting the delivery of developmental services.

PART I: WHAT IS A REGIONAL CENTER?

A regional center is a community-based non-profit corporation chartered in state law and operating under contract with the state Department of Developmental Services. A regional center has as its mission to enable people with developmental disabilities to live more independent, productive, and normal lives, and to minimize the risk of developmental disabilities and ameliorate developmental delays in infants and young children who are at risk for developmental disabilities.

A developmental disability is a condition that originates before a person reaches age 18, is expected to continue indefinitely, and constitutes a substantial impairment. There are five categories of disability: mental retardation, cerebral palsy, epilepsy, autism, and disabling conditions closely related to mental retardation or requiring treatment similar to that required by a person with mental retardation.

There are 21 regional centers in California, each serving a designated geographic area. They accomplish their mission through the coordination and provision of services and supports in accordance with the mandates of the Lanterman Developmental Disabilities Services Act and the Early Intervention Services Act. Specifically, the services provided directly by regional centers are: intake and assessment for diagnosis and eligibility determination; individualized planning and coordination of services; advocacy; family support; assurance of service quality through monitoring, auditing, technical assistance and training to its service providers; and resource development. All services provided directly by regional centers as well as services purchased by regional centers for consumers and families are provided without regard for family income. The regional center program is funded through a combination of state and federal funds, totaling approximately \$2 billion for FY 2002-03.

Regional centers currently serve approximately 180,000 people throughout the lifespan. Approximately 40% of people served are children birth to 13 years of age, and another 16 % are adolescents and young adults aged 14 to 21. Fully 50% are people with mental retardation. Another 31% have mental retardation coupled with one or more of the other developmental disabilities – epilepsy, cerebral palsy, autism. Although autism, either alone or coupled with another disability, presently affects about 11% of the regional center client population, it increased in California by a staggering 273% between 1988 and 1997. The vast majority (92%) of children under 18 years of age live at home with their families. Another 48% of adults also live with their families. Only 4% of people with developmental disabilities reside in state developmental centers.

Most of the direct services received by clients of the regional center are provided by independent service providers under contract with regional centers. These individual professionals and organizations provide a wide range of services and supports, including, for example, residential care, day programs, respite, transportation, and behavior management. Regional centers also work with generic agencies such as local school districts, mental health departments, Medi-Cal, the Social Security Administration, and the state Department of Rehabilitation to ensure that regional center clients receive services from generic agencies.

Part II: DEVELOPMENT OF REGIONAL CENTERS AND THE ENTITLEMENT

Note. Knowledge and understanding of the development of the regional center system, the entitlement to services, and the funding of the system is critical to an understanding of the discussion of issues and recommendations that follow. Readers who are familiar with regional centers and the related issues may wish to review this section on the history only briefly.

Parents of children and adults with developmental disabilities, as well as professionals working in the field, are intensely passionate about the “entitlement” defined in the Lanterman Act and they value it highly. To understand why this is so, it is necessary to understand the history of the Lanterman Act and the development of the regional center system. (A more detailed account of the development of the regional center system can be found in the publication, *The Ever Widening Circle of Inclusion*, available from Frank D. Lanterman Regional Center.)

Prior to the establishment of the regional center system that began with two pilot projects in 1966, the only care provided by the state to children and adults with developmental disabilities and their families was custodial care in large state institutions for people with mental retardation – if the families were able to find an opening. At that time, approximately 13,000 people lived in such institutions and another 3,000 were on the waiting list for placement

If they chose to care for a child with developmental disabilities in the community or if their child was on the waiting list for a state hospital, families were essentially on their own. With the exception of very limited post-hospital care in licensed homes in the community for people who could not return to their family homes, there were no community services and few if any school programs. In response to this situation, parents engaged in self-help, establishing voluntary organizations to create day activities for children and adults and group homes as alternatives to the state hospital.

Then, in 1965, the California Legislature passed landmark legislation (AB691 Waldie) to establish a community-based alternative to institutional care for people with mental retardation (later expanded to include other developmental disabilities). Regional centers were to be the mechanism through which services in the community were coordinated. The act called for a shift in the state’s responsibility for people with mental retardation from the point where they enter a state hospital to the point where they are diagnosed. In urging passage of the bill, Governor Pat Brown stated that a major goal in establishing the first two regional centers was, “...education and rehabilitation, not merely protection and custody...If [people with mental retardation] can become more self-sufficient and productive, some may become taxpayers and more active participants in our society. In any event, they will require less expensive services from society than if they were totally dependent.”

In their first year of operation, the two pilot regional centers served 559 people who were on the waiting list for state hospital placement. The first year’s budget was less than \$1 million dollars, for an average service cost of \$1,728 per person. Based on a positive evaluation of the pilots, the Legislature expanded the model statewide. The system eventually grew to 21 regional centers, chartered in state law but operated as private non-profit corporations under contract with the state (AB 225, the Lanterman Mental Retardation Services Act, later to become the Lanterman Developmental Disabilities Services Act).

By 1975, the regional center system was serving 33,833 people with a budget of \$47,980,527, for an average cost of \$1,418 per person. The population of state institutions had fallen by almost 22%, to 10,200. During these years, the program was funded almost entirely by state general funds and each regional center was given an annual budget allocation. Sometimes, centers' allocations were insufficient to meet the service need, and the Department of Developmental Services (DDS) would seek supplemental appropriations from the Legislature. For their part, centers found it necessary to establish priorities for services and waiting lists for new clients or for services that were not of an urgent nature.

During the decade 1975-85, the eligibility for regional center services was expanded to categories of developmental disabilities beyond mental retardation, and the requirement for an individualized planning process (IPP) was added. The service model was generally one of structured programs that served groups of people who fit predetermined criteria. Although community-based, these programs were typically segregated. Services included group homes, sheltered workshops and day activity centers, and transportation to these settings. Family support in the form of respite service was added in 1977.

By 1985 the annual regional center budget had risen to \$317,803,208 and the centers were serving 78,312 people at an average cost of \$4,038 per person. The state hospital population had declined over 30% from a decade earlier, to 7,100 people.

In the early 1980s, state budget deficits resulted in reduced funding for regional centers. Centers were required by DDS to implement cost-saving strategies, such as establishing service priorities and making categorical cuts in services, in order to keep their doors open and provide services for the entire year. In response, the Association for Retarded Citizens (ARC) brought suit against DDS and the regional centers, claiming that the Lanterman Act was an "entitlement to services" and that these cost-saving strategies were illegal.

The California Supreme Court found for ARC in this case, ruling that the Lanterman Act "defines a basic right and a corresponding basic obligation...[T]he right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services". The Court further found that, "The rights of developmentally disabled persons and the corresponding obligations of the state toward them under the Lanterman Act are implemented in the Individual Program Plan (IPP)." *It is the IPP, said the Court, that defines the entitlement for each individual, and the services and supports listed in that document must be provided.* At the same time, however, the Court stated, "It is simply not the case that the Act fails to establish a maximum of services to which the developmentally disabled person is entitled....[We] conclude that it grants the developmentally disabled person the right to be provided at state expense with only such services as are consistent with its purpose." The purpose referenced by the Court is to provide people with developmental disabilities the services that will enable them to lead more independent and productive lives.

Equally important in the ARC decision were the Supreme Court's conclusions that regional centers may spend no more money than is appropriated by the Legislature. Furthermore, the Court

concluded that, "so long as funds remain, the right must be implemented in full; as soon as they are exhausted, it can no longer be implemented, but may be financed through an additional appropriation if the legislature so chooses." Alternately, the Court said, the Legislature could resolve the crisis by reducing the entitlement. This decision created the "great dilemma" for regional centers that still exists today. The dilemma is how to provide all the services and supports mandated by an individually and broadly defined entitlement to all eligible consumers throughout the term of the contract and not exceed a set appropriation.

Another event occurring in 1985 would have a significant impact on regional centers' funding and operations. Before 1985, regional centers were almost entirely state-funded. That year, however, the state was approved to participate in the federal Home and Community-Based Waiver (HCBW) program. The HCBW program grew over subsequent years to be worth hundreds of millions of dollars annually to the state. At the same time, it brought to regional centers a large number of regulation-based compliance requirements. It also required regional centers to vendor virtually all service providers satisfying minimum requirements to ensure consumer and parent "choice". This requirement became a significant cost driver, making it increasingly difficult for regional centers to manage the scope and amount of services purchased and to enforce standards for service quality.

Much of the HCBW funding generated by the regional centers was returned to the state's general fund rather than supplementing regional center budgets. Access to such supplementary funding would have enabled regional centers to keep pace with community compensation and other costs for both service providers and regional centers. Over the years, regional centers' inability to do this has had a deleterious affect on the quality of services provided to consumers and their families and, in some cases, has resulted in service providers closing their doors.

The decade following 1985 was a time of significant social and economic change that resulted in increasing tension between the entitlement and budget realities. Changes occurred in the economic condition of the state and nation, in the service model for people with developmental disabilities, and in an unprecedented expansion of how the entitlement was defined. This apparent broadening of the entitlement resulted in a corresponding increase in the types and number of services regarded as necessary and appropriate for people with developmental disabilities. This in turn led to increased expectations on the part of consumers and their families regarding the definition of service "need."

In 1991, owing to a nationwide recession, California's budget deficit exceeded \$1.5 billion. The state implemented a budget methodology called "unallocated reduction" that required regional centers to prepare expenditure plans outlining how they would reduce their budgets but still meet all mandates of the Act. This strategy relied on voluntary cooperation of consumers, families, and service providers, with each regional center working with its own community to create a unique expenditure plan in accordance with guidelines issued by DDS. DDS retained the authority to disapprove all or part of a plan.

The following year the budget situation worsened and the state deficit grew to nearly \$11 billion. As a result, regional centers lost 23% of their funding. The state Legislature enacted SB 485 in an attempt to ensure access to services within the limits imposed by the budget while maintaining the entitlement to services. This bill stated in part, "In order to ensure that services to eligible

consumers are available throughout the contract period, regional centers shall administer their contracts within the level of funding available within the annual Budget Act...Regional centers shall implement innovative, cost-effective methods of service delivery." The bill required parents to provide for their child with a developmental disability as they would for a child without a disability. The bill also waived certain regulatory requirements, thereby giving centers authority as well as flexibility to more effectively manage their budgets. This authority ended in January of 2002 when the bill "sunset."

Significantly, during this same year, the Legislature passed a bill (SB 1383) that made significant changes to the Lanterman Act. This bill updated the philosophy and embraced the concept of "empowerment," giving consumers and families more choice and more authority to make decisions about their lives. It also greatly expanded the range of services and supports available to consumers and families. And while the Act cautioned that these changes should not be construed as expanding the entitlement, they did, in fact, result in a significant expansion due to a rise in expectations among consumers and their families.

SB 1383 added two new service directions to the Lanterman Act. The first was an endorsement of services provided in "natural environments" to promote community integration. These services utilized strategies such as trained aides providing individual support to children and adults with developmental disabilities that would allow them to be included in activities with non-disabled peers in integrated environments. The second was "supported living," providing "opportunities for adults with developmental disabilities, regardless of the degree of disability, to live in homes that they own or lease with support available as often and for as long as it is needed." (Section 4689.) At the time SB 1383 was passed, some adults with developmental disabilities were living on their own with modest support (called "independent living" services). Supported living constituted a profound change, however, in that it proposed that any person, regardless of type or severity of disability or support needed, could also live on his own.

In 1993, adding to the complexity of the funding situation in developmental services in California, the state enacted SB 1085, authorizing California's involvement in the federal Part H Early Intervention Program (Early Start) for infants and toddlers. California already had a well-established early intervention program that had demonstrated effectiveness in serving infants and toddlers with developmental disabilities. The state chose to accept federal funding and expand the services to at-risk children. This decision brought with it significant cost increases. The federal requirements included an extensive list of services and supports that regional centers were obligated to offer families. At the same time, regional centers were prohibited from asking parents to share in the cost of services. They were also prohibited from using a family's health insurance, except with the parents' expressed consent. As a result, in addition to a significant increase in the number of children served, there were increases in the number and kinds of services provided to each child, and a corresponding increase in costs.

During this same period, the state settled a class action lawsuit, *William Coffelt, et al. v. Department of Developmental Services, et al.* that required a further reduction in the population of developmental centers. DDS established the Community Living Options Initiative that called for moving 2,000 residents of developmental centers into the community over five years. The cost of this initiative was estimated to be one-third of a billion dollars, most of which was to be funded by

an expansion of the HCBW program. This decision increased the state's reliance on federal funds and imposed additional compliance requirements on regional centers' direct services and operations.

By 1995 the developmental center population had fallen to 5,100 and regional centers were serving 129,230 people. The annual budget for regional centers had risen to \$941,515,000, for an average cost of \$7,285 per person. By that time, nearly 60% of funding for regional centers came from federal financial participation.

In 1998, a bill was passed in the California Senate requiring DDS to address the inequities in the rate system applied to developmental services. That bill, SB 1038, called upon DDS to engage stakeholders in a "system reform" effort to address structural and rate reforms aimed at developing equitable and cost-effective payment systems based on performance and consumer outcomes. By 2001, this reform process was stalled.

The state fiscal crisis of the early 1990s resulted in long term unintended consequences to the regional center system. Despite the fact that the state eventually recovered from the recession and went on to have large budget surpluses and a strong economy for a number of years, the regional center system did not benefit proportionately from the years of plenty. The unallocated reductions in the budget appropriations were never fully restored in subsequent years, and in some measure they continue to this day. At the same time, virtually no cost of living adjustments have been provided for the entire decade. Salaries have stagnated, affecting service quality as well as availability, as some providers have been forced out of business.

The repeated use of the unallocated reduction methodology created increasing disparities in purchase of service funding across regional centers. This was due to the wide variation in regional center expenditure plan proposals and the varying degrees of success in plan implementation that was highly dependent upon community support. In addition, this cost saving methodology magnified the existing disparity in purchase of service spending across regional centers. For example, the projected per capita spending for 2002-03 reported by the 21 regional centers ranged from a low of \$7,300 to a high of \$13,900. When DDS allocated the \$52 million in required savings across regional centers, it did so proportionally based solely on the number of clients rather than on per capita spending.

In 1997, the Legislature authorized the Bureau of State Audits to conduct an audit of the budget and allocation process used by DDS to fund regional centers. The Bureau concluded that the process did not ensure that clients throughout the state have equal access to needed services. The report concluded that insufficient state funding and more than \$106 million in budget cuts in four years had undermined the success of the system. Subsequently the Legislature mandated that DDS determine the reasons for the lack of equal access and make recommendations to correct the problem. The study of the problem is in progress, and long overdue for completion.

More recently, funding has been provided piecemeal by the state for specific purposes, such as meeting federal requirements for individuals participating in HCBW and Early Start, providing intensive early intervention services for children with autism, and continuing movement of state developmental center residents into the community. At the same time, regional centers remain under funded in their core services and programs.

The current fiscal crisis in California has created an unprecedented shortfall in state revenues and a budget deficit estimated by the governor to be more than \$30 billion for fiscal year 2002-03. As a partial response to the crisis, DDS proposed the establishment of "statewide service standards" for regional centers – a proposal that was widely rejected by advocates and some providers as signaling the death knell of the entitlement. As a result, the Legislature once again chose to use the failed methodology of unallocated reductions, asking regional centers to develop expenditure plans that would reduce spending in the system by \$52 million.

The projected deficit in FY 2002-03 for the regional centers system is much greater than \$52 million. Regional centers are projecting an additional deficit of up to \$85 million, even if their expenditure plans are 100% successful. Such a sizable projected deficit for regional centers in a year when the state is also suffering from a huge deficit raises the question of whether and how the current entitlement to services can continue to be supported. A recent analysis by the non-partisan Legislative Analyst Office (LAO) contains the conclusion that, despite budget reductions, tax increases, fund transfers, loans, and the like, a \$6 billion deficit still exists in the current year, and the deficit is likely to be more than \$20 billion in FY 2003-04. The LAO further projects that shortfalls of between \$12 billion and \$16 billion will continue until 2007-08.

PART III: THE ISSUES

1. *While the Lanterman Act defines an entitlement that is non-prescriptive, highly individualized, and, in effect, unlimited, it is funded through an annual budget appropriation that is finite and vulnerable to economic downturns.*

The Lanterman Act defines an entitlement that has evolved to be essentially unlimited. There is no defined benefit as there is with most entitlements, but a right, imposed by legislation and strengthened by judicial action, to whatever services and supports are needed to enable a person with developmental disabilities to lead a more independent and productive life in the community. From an economic perspective, current policy framework makes it difficult if not impossible for regional centers to effectively manage this entitlement.

The broadness is especially evident with regard to services for children. The Act outlines a wide range of services that may be provided to ensure that families are able to maintain their children at home. For example, Section 4646 states: "the IPP shall include a family plan component which describes those services and supports necessary to successfully maintain the child at home. Regional centers shall consider **every possible way to assist families** [emphasis added] in maintaining their children at home...." Further: "if the parent of any child receiving services and supports from a regional center believes that the regional center is not offering adequate assistance to enable the family to keep the child at home, the parent may initiate a request for fair hearing...."

The services required to keep a child at home are described as including any and all that "maximize opportunities and choices for living, working, learning, and recreating in the community (Section 4640.7)." In particular, they are intended to allow the consumer "to increase control over his or her life, acquire increasingly positive roles in community life, and develop competencies to help accomplish these goals (Section 4646.5)."

The goals of the Lanterman Act are addressed by an increasingly broad and expensive array of services and supports. Further, the state has established no service standards or priorities. All services in a consumer's IPP are viewed as equally important when funding decisions are made. There is no requirement for share of cost and no means testing for income eligibility. State and federal mandates aimed at empowering parents have greatly expanded their role in deciding what services and supports are necessary for their children.

Without a clearer definition of the entitlement, the rising expectations of families result in an expansion of what is considered a "necessary" service, particularly among parents who are more highly educated. As a result, oftentimes, these children receive proportionately more services than the children of less advantaged families. For example, one regional center that reports expenditures by health district found that the poorest district was home to 15% of the regional center client population living at home but consumed only 9% of its purchase of service budget. The service coordination process ensures that all consumers receive the basic complement of services required to meet the purposes of the Act, but increasingly the differences in parents' abilities to advocate successfully for their children result in inequities in the provision of services.

Juxtaposed with this increasingly broadly defined entitlement is an annual budget process with set appropriations that is vulnerable to economic downturns. Recessions are cyclic, but the state Legislature has generally not chosen to restore earlier cuts to regional centers in times of surplus. Furthermore, the system of state control includes significant compliance requirements, but gives regional centers no effective tools for managing their purchase of service spending. In 1991, with SB 485, the state gave regional centers the authority and flexibility they needed to manage their budgets more effectively, but these legislative changes “sunset” in January of 2002. (See Recommendation 1.)

2. *The cost of the entitlement continues to increase due to the shifting model of service provision and the proliferation of services designed to meet individual needs.*

Since the promulgation of the Lanterman Act, the model that guides service delivery for people with developmental disabilities has changed radically from one of institutionalized custodial care to one based on the “inclusion” mandate – emphasizing full participation of people with developmental disabilities in the community. During this time, the variety of services and supports available to people in the community has continued to expand and the corresponding cost per individual has increased markedly. In addition, advances in knowledge and innovations in technology, as well as a lack of rigorous criteria for vrending services, have resulted in a large number of new service types, some of which are very costly and, sometimes, of questionable effectiveness. A brief discussion of two services sheds some light on the dynamics of the cost increases.

Supported living. A major service innovation has been supported living, wherein a person with a disability receives whatever services and supports are necessary for him to live on his own in the community. People qualify for supported living regardless of the nature and extent of their disabilities and receive support “as often and for as long as it is needed.” Furthermore, it is intended that “the consumer’s preference shall guide decisions concerning where and with whom he or she lives” (Lanterman Act, Section 4689).

This innovation has provided opportunities for people with disabilities that would have been deemed impossible in the early days of the Lanterman Act, and certainly before. Consider the example of one person who has benefited greatly from the availability of supported living. Cynthia (not her real name) is a woman in her late 20s who has severe cerebral palsy (spastic quadriplegia), is non-verbal, and needs assistance for virtually every aspect of personal care and activities of daily living. With the help of 24-hour a day support and advanced technology, Cynthia lives in her own apartment. As recently as 20 years ago, Cynthia would have been institutionalized. Now she lives on her own, takes college courses, and socializes with her friends in the community.

But also, Cynthia’s remarkable achievement has cost considerations. While this service was intended to be “cost-neutral,” the reality is significantly different in many cases. The average cost of community care at one regional center is \$3,500 per month (\$42,000 per year), but supported living can cost more than twice that amount. Understandably, supported living has become a preferred living arrangement for an increasing number of consumers. Advocates and an increasing number of families view this living option as being available to and appropriate for everyone.

Intensive behavioral services for children with autism. Recent research has demonstrated that intensive early intervention with a comprehensive behavior-based program can significantly

improve communication and social skills for children with autism. These programs are expensive, both because they are intensive (typically 25-30, but sometimes up to 40 hours per week) and because their costs cover the services of the technically trained interventionists as well as professionals supervising the interventionist. The cost of intensive behavior programs can range from \$35,000 to \$90,000 per year.

The number of children receiving intensive behavioral services has increased significantly over the past five years. This increase is due to two factors. First, the incidence of autism has greatly increased in the state as well as the nation (e.g., a 273% increase in California between 1988 and 1997), resulting in more children for whom such interventions are appropriate. Second, increasing numbers of parents are learning about these services and requesting them for their children, even though they may not be effective for their specific situation. (See Recommendation 1.)

3. ***The Lanterman Act gives parents the leadership role in determining what services will be provided to their children with disabilities but does not address their financial responsibility or require any sharing of cost.***

The Lanterman Act is explicit in giving parents the leadership role in determining what services will be provided to their children by the regional center. For example, the Act describes the planning process and services provided by the regional center as being “centered on the individual and the family...and [taking] account of the needs and preferences of the individual and the family.” It is the further intent of the Legislature to ensure that the “provision of services to consumers and their families be effective in meeting the goals stated in the IPP, [and] reflect the preferences and choices of the consumer...(Section 4648).” The Act also gives consumers and families broad rights to appeal if they believe the regional center is not offering them adequate assistance.

The entitlement defined by the Lanterman Act differs significantly from virtually every other federal or state entitlement program in that it does not require families to share in the cost of services, nor does it require means testing for income eligibility. Research focused on health and social services has demonstrated that consumers who are required to share the cost of services are more likely to value the services they receive and less likely to utilize unnecessary services. At the same time, cost sharing needs to be held at a level that does not prevent families from accessing necessary services.

Until the provision “sunset” in January of 2002, the Lanterman Act required regional centers to “...take into account, in identifying the consumer’s service needs, the family’s responsibility for providing similar services to a child without disabilities (Section 4791).” The elimination of this provision has, in many cases, resulted in regional centers paying for a variety of services that parents themselves would be obligated to pay for if their children were not disabled. Typical of these are swimming lessons, camp, and Saturday recreation programs. Families often ask regional centers to pay for these services regardless of their own financial resources.

Prior to the writing of the Lanterman Act, the only responsibility the state accepted for people with developmental disabilities was to provide institutional care. In contrast, some people now interpret the Act as giving the state the responsibility to meet all of the service and support needs of people with developmental disabilities, with no corresponding financial obligation on the part of parents. (See Recommendation 3.)

4. *The Lanterman Act provides an ambiguous definition of the entitlement and a broad appeal provision that allows consumers and families to appeal virtually any decision made by a regional center. These two factors contribute to an environment that encourages families to appeal and administrative law judges to exercise broad discretion in interpreting law and regulation in their fair hearing decisions – decisions that de facto expand the definition of the entitlement.*

The Lanterman Act gives consumers and families broad appeal rights. For example, Section 4710.5 states: “Any applicant for or recipient of services, or [his/her] authorized representative, who is **dissatisfied with any decision or action of the service agency** which he or she believes to be illegal, discriminatory, or **not in the applicant or recipient’s best interests** shall...be afforded an opportunity for a fair hearing.” [Emphasis added.] This provision gives wide berth to parents who are unhappy with any aspect of their relationship with the regional center. Coupled with the leadership role given to parents in determining what services are necessary for their child with developmental disabilities, the provision allows for appeals to be filed with no initial determination of merit and without regard for whether the denied service meets the tests of necessity and appropriateness.

An extreme example of this was an adult client of a Southern California regional center who at one time had more than 60 separate appeals pending in the Office of Administrative Hearings. One of the appeals related to her request for the regional center to provide her with a paid attorney advocate. She could not seek help from attorneys in the Office of Clients’ Rights Advocates or Protection and Advocacy, Inc., since she had already disqualified all of them by filing complaints against them with the California State Bar.

Combined with the unlimited right to appeal is a significant amount of ambiguity in the Lanterman Act as to the definition of this broad-based, individually determined entitlement. Because of this ambiguity, the entitlement is subject to wide ranging interpretation by administrative law judges presiding over fair hearings. Judges use broad, sometimes overly broad, discretion in deciding appeals and issue decisions that in effect expand the definition. In some circumstances they abuse this discretion and grant an appellant more than was requested or something that was not part of the appeal in the first place.

It is clear that administrative law judges often incorrectly interpret the Act out of a desire to provide relief to a family. Certainly, the lack of precision found in the Lanterman Act contributes greatly to this by giving judges great leeway in interpretation. Some examples of decisions made by judges from the OAH demonstrate how these two factors result in decisions that are inconsistent with the letter and intent of the Lanterman Act.

Example 1

An ALJ ordered a regional center to pay a family \$5,500 per month, and \$37,000 retroactive reimbursement, to care for their six-year-old son who had multiple physical disabilities and developmental delays. This amount is what would have been required to maintain the child in an Intermediate Care Facility and was characterized by the judge as reimbursement to the family for the services of the father who elected to be the sole care provider for his son. There was no expectation on the part of the judge that the family would use the funds to retain outside caregivers to relieve the

father from the constant responsibility. Instead, the “additional support means only that the family’s financial burden of caring for Claimant at home will be lightened and that they may be able to begin to climb out of the financial morass into which they have descended over the last six years.”

The following excerpt from that decision shows clearly how the ambiguity of the Act allows judges to exercise a level of discretion that, in the end, violates the intent of the Act: “[I]t is necessary to consider whether reimbursement is appropriate in this case. The Lanterman Act does not specifically authorize reimbursement of money spent or compensation for services that have been improperly denied. However, that lack of statutory authorization is not necessarily dispositive of the issue. If the Lanterman Act is to be applied as the legislature intended, reimbursement must be available where equity requires it.”

Example 2

The regional center was funding respite services for 120 hours per month, per child, to the mother of twins diagnosed with autism and behavior challenges. The center proposed reducing the service, first, to 80 hours per month for each child and, subsequently, to 60 hours. The mother was requesting less than 120 hours per child, but more than the regional center was offering, and she requested a fair hearing.

The ALJ ordered the regional center to “provide the twin claimants with continual twenty-four (24) hour one on one daily supervision, and their mother with daily undisturbed period of eight hours respite from her parental obligations (sic).” The Superior Court subsequently ruled that the ALJ had abused his discretion, stating that there was no substantial evidence in the administrative record to support the decision to require the regional center to furnish the mother with daily supervision for each child for 24 hours per day.

While fair hearing decisions do not set legal precedents, other parents and their advocates treat them as such by citing them in later service requests or appeals. Further, advocates disseminate certain of these decisions (e.g., on the Internet) in order to encourage other parents to use them as though they were precedential in their dealings with the regional center. A second consequence of these flawed interpretations is unnecessary costs – not only the cost of providing services that fail to conform to the Lanterman Act, but also the substantial cost associated with conducting state level appeals and challenging OAH decisions in the Superior Court. There is no review of individual judges’ decisions prior to their release by OAH. In addition there is no provision for administrative review by the Department of Developmental Services or authority for the Director of DDS not to certify a decision. The only alternative open to regional centers and families is to appeal the decision in Superior Court. (See Recommendation 10.)

5. ***Generic resources often fail to meet their rightful obligation to regional center clients. This is due to a lack of a clear legislative mandate of generic services vis-à-vis regional centers, a lack of adequate funding of these generic services, and a perception among the generic agencies that the regional centers have the "deep pockets." As a consequence, regional centers are increasingly and inappropriately called upon to pay for these services.***

The Lanterman Act mandates that regional centers be the payer of last resort. If the consumer or family has access to generic agencies or (for consumers over the age of 3) private insurance that would normally cover a required service, these other resources should be used first. Only if there is no other source of funding is the regional center obligated to purchase a service.

Because of their own budget concerns or because they perceive regional centers as being relatively well-funded, generic agencies are increasingly unable or unwilling to serve people with developmental disabilities. For example, the public health care and mental health systems in California have been particularly hard hit in recent years and it is acknowledged that they are severely under funded. Partly as a result, these systems are failing badly in their attempts to meet the needs of MediCal beneficiaries and the uninsured, two groups that include a large proportion of the regional centers' consumer population.

More notable, however, is the failure of the relatively well-funded school districts to provide education and related services in accordance with the requirements of the federal Individuals with Disabilities Education Act (IDEA). Often, schools encourage parents to seek services – which the schools should be providing – from the regional center. For example, one school district in Southern California makes further negotiation with parents on a needed service contingent on the parents' appealing a regional center's denial of service. Another local school authority has required parents to sign a confidentiality agreement that prohibits them from disclosing to the regional center what services the school is providing to their child.

Administrative law judges from the OAH have contributed to this problem by making decisions based on a lack of understanding of IDEA. For example, ALJs have ordered regional centers to fund behavior modification and discrete trial training services for children with autism when at least some of those services fall under the obligation of the local school district as required by IDEA. In some of these cases, families have been unhappy with the service provider or the type of behavioral training offered by the school district, and the ALJ has ordered the regional center to fund all of what the family requested, notwithstanding what was available from the school district. In other cases, the school district has offered to provide half or less of the recommended services and the regional center has been ordered to fund the balance.

Such orders demonstrate disregard for the fact that IDEA requires the school district to provide all services necessary to afford the child a free appropriate public education. Such services can include behavioral services and any other service necessary to bring the child to the point where he can benefit from his educational program. For example, in the case of Battle v. Commonwealth of PA. (3rd Cir. 1980) 629 F.2d 269, the court specifically stated that “[w]here basic self help and social skills such as toilet training, dressing, feeding, and communication are lacking, formal education begins at that point. If the child masters these fundamentals, the education moves on to more difficult but still very basic language, social and arithmetic skills, such as counting, making change, and identifying simple words.” In County of San Diego v. California Special Education Hearing Office (9th Cir. Cal. 1996) 93 F.3d 1458, the district court, in determining whether a particular day program was providing an “educational benefit” for a child classified as seriously emotionally disturbed, upheld the lower court’s standards for measuring educational benefit under IDEA, including the following: “educational benefit is not limited to academic needs, but includes the

social and emotional needs that affect academic progress, school behavior and socialization.” (See Recommendation 1.)

6. ***The community-based service system that was initially parent-led and non-profit has grown to include a substantial number of for-profit services and individual service providers who actively market directly to families.*** 4

In the beginning, since public programs for people with developmental disabilities were extremely limited and focused on institutionalization, parents began developing services for their children on their own. Parent-led groups such as the Exceptional Children’s Foundation (ECF) in Los Angeles and Aid to Retarded Citizens (ARC) in San Francisco provided support to families and programming for people with mental retardation by operating private schools, activity centers, sheltered workshops, and residential services. In response to parent requests, church groups and other charities also began offering similar programs.

The current service system stands in distinct contrast to that historical one. Many of the original parent-led agencies such as ECF and ARC have survived as non-profit organizations governed by volunteer boards of directors. They engage in fundraising to supplement their public funding streams and any “surplus” funds are put back into programs for the benefit of consumers. Since these programs tend to be the older ones of the system, they are most likely to be hampered by years of inadequate rate increases from the state. Some have gone out of business and been supplanted by newer, for-profit services that receive a higher rate for the same service. For example, one Southern California day program provider had received the same rate – \$26.85 per day per client – for 10 years. Unable to sustain programming on that rate, the organization closed its doors. Services to its clients were transferred to a new, for-profit provider whose rate was set at \$42.61.

These newer, for-profit providers are highly motivated to expand their market share. To achieve market expansion, they aggressively market their services not only to regional centers but also directly to consumers and families. As a result of such marketing efforts, the variety of services that are purchased by regional centers expands along with the number of families who request these services even when they may not be appropriate. Because of the requirement of federal financial participation to give consumers and families “choice” of services and providers, the regional center is generally obligated to vendor a service if that service meets the minimum standards established by the state. (See Recommendations 4, 5, and 6.)

7. ***Parent choice is a predominant determiner of which services become vendored and which services are purchased.***

The Lanterman Act authorizes regional centers to purchase services or supports “from any individual or agency which the regional center and consumer or...his or her parents, legal guardian, or conservator, or authorized representative determines will best accomplish all or any part of that consumer’s program plan.” Further, the highest preference is to be given to “those services and supports which would allow minors...to live with their families, adult persons...to live as independently as possible in the community, and that allow all consumers to interact with persons without disabilities in positive, meaningful ways.” (Section 4648.)

Frequently, parents independently identify a service that they believe will be beneficial for their child. They may hear testimonials about the service from other parents, find out about the service through Internet communications, or hear about it through marketing efforts by the service provider. Some request a list of all services the regional center provides, with the expectation that all listed services are options for them to choose from, regardless of their child's need for those services.

Out of a true belief in the service or a sense of urgency to find something that will help their child, the parents ask the regional center to purchase the service for their child. The regional center is then obligated to vendor the service provider as long as that provider meets minimum standards. Sometimes the request for a new service is made outside of the Individual Program Plan process if parents learn about a service after the plan is completed. On occasion, parents begin a service and then ask the regional center to fund it retroactively.

When they independently select services for their children without the participation of knowledgeable professionals, parents place themselves in the position of making decisions about quality and effectiveness that they may not be qualified to make. There is a legitimate role for clinical expertise in decision-making in developmental services, just as there is in health care. Particularly as services become more technically advanced, it is increasingly important for parents and professionals to work collaboratively in determining which services are appropriate for addressing the goals and objectives of the IPP for a particular child. (See Recommendation 7.)

8. *The regional center functions as a purchaser of services, but has little control over how much it pays for services. The current methods used to determine rates contribute to rate inflation and inequities in rates across programs.*

The rates paid by regional centers for purchased services are determined in several different ways. Each of these ways contributes to a rate system that is inequitable in some cases and inflationary in others.

Inequities. New programs (e.g., adult day programs) are assigned a temporary rate by DDS based on rates of existing similar programs. After a one-year period, the department sets a permanent rate, based on a statement of costs submitted by the program. For example, three recently vendored programs in Southern California received an average rate of 11% more than the existing programs on which their temporary rate was based. The program submits the cost statement directly to DDS but is not required to submit supporting documentation to validate the figures in the cost statement.

While regional centers may audit a cost statement submitted by a new program, they generally have few, if any, resources for conducting such an audit. In addition, the time allowed by DDS for regional center review generally precludes them from completing a valid audit prior to the department making its final determination of rates.

Once a program has its permanent rate, it receives periodic cost-of-living adjustments (COLA) based on a percent determined by the Legislature and/or demonstrated costs. COLA amounts over the years have not kept established programs at parity with new programs. As a consequence, more recently established programs typically receive significantly higher rates than programs that provide

the same type of service but have been operational for a substantial period of time. (See the example on page 16.)

Rate inflation. Services for which MediCal rates have been established – e.g., professional services such as psychology or occupational and speech therapy – are supposed to be paid by regional centers on that basis. Regional centers, however, are often unable to find a professional willing to work for the exceptionally low MediCal rates, and they find themselves in the position of having to pay whatever providers ask in order to obtain the service. A similar situation exists with services that are paid on the basis of what is usual and customary (the average rate charged by similar providers in the community). These providers also are not bound by the usual and customary rate and may be paid significantly more if the regional center cannot find a sufficient number of providers to meet their needs.

Some providers, such as speech therapists, elect to work for the school system rather than negotiate with regional centers, since the established rates paid by the Department of Education are significantly higher than those paid by DDS. In heavily populated areas being served by multiple regional centers, providers sometimes set their rate equal to the rate of the highest-paying regional center in the area. As a result, all centers in the area may end up paying this highest rate. If a regional center resists paying a requested rate, the provider informs the center that it will no longer provide services. These factors have led to significant rate inflation, particularly with regard to Early Start services where there are too few providers to satisfy the demand. For example, in Southern California some speech therapists are paid \$125 or more per 50-minute session as opposed to the \$46.82 per hour paid under the MediCal program.

Two final examples demonstrate other aspects of rate inflation among for-profit providers. The first example relates to the relatively new intensive behavioral services provided to children with autism. This type of service may include, not only an hourly charge for the direct provision of services, but also charges for professional supervision of the person providing the direct services. One Southern California program bills three separate charges for supervision above and beyond the cost for the direct intervention. These charges are attributed to three different levels of supervision of the person providing the direct service. The second example is provided by supported living services. Some of these programs charge a separate “administrative fee” over and above the cost of direct support. This fee is applied for each client regardless of the number of clients a program serves. In virtually no other area of human services, such as medical care and social services, are payers asked to pay a designated cost for supervision or administration. Such costs are traditionally built into overhead and, when charged as such, generally constitute a smaller percentage of the total cost of services than when they are itemized separately. (See Recommendations 5 and 9.)

9. *The regional center has little capacity to ensure the quality of services it purchases for consumers.*

The Lanterman Act gives regional centers a general responsibility for monitoring the “quality and cost-effectiveness” of services they purchase. At the same time, their staffing patterns provide them with insufficient human resources to establish and carry out effective quality management programs. The core staffing formula used by DDS to determine funding for regional centers provides for two types of regional center employees whose activities are in any way directly related to quality

monitoring. One is the fiscal monitor whose activities, while of great importance, are arguably unrelated to service quality. The other is Quality Assurance (QA) staff whose designated responsibilities relate to monitoring the quality of licensed residential services. QA staff members are required to monitor residential services twice a year – once unannounced and once announced. In addition, every three years they conduct a thorough review of each facility and its residents' records. There is no corresponding explicit requirement and no designated staff for monitoring other types of services, such as day activities, supported living services, and behavior management services, or any other specialists or professionals.

Regional centers have no effective authority for engaging service providers in activities aimed at raising the level of quality above the minimum regulatory requirements. Some centers have attempted to encourage quality improvement or quality enhancement activities for program services, including supported living, residential, and day programs. But these centers have had to base their activities on the voluntary cooperation of service providers. Providers who do not wish to participate can point to the minimum requirements for vendoring stated in the California Administrative Code and claim they are not required to perform above that level. Parent choice of the type required under federal financial participation is also a powerful force in ensuring that services continue to be used, even in the absence of evidence that they are successful in achieving desired outcomes.

The Lanterman Act was amended in the early 1990s to require regional centers to be accountable for specific outcome-based performance objectives. Through these objectives, regional centers are asked to demonstrate that they are helping consumers “achieve life quality outcomes” and “meaningful progress above the current baselines (Section 4629).” In contrast, no such requirements apply to providers who serve regional center consumers and their families. The result is a system under which regional centers wishing to improve the quality of services they purchase must use various strategies to persuade service providers that achieving a higher level of quality will work to their advantage. (See Recommendations 6.)

10. *There is no mechanism to ensure that new service modalities are effective.*

Interventions intended to address medical, psychological, or other developmental challenges should be subjected to scientific study of their effectiveness before they are used routinely. The standard method for addressing the question of effectiveness is the controlled study. Controlled studies employ service providers carefully trained to deliver the intervention in a standardized manner, patients or clients selected to receive the intervention according to explicit qualifying criteria, and a random process to assign these people to experimental and control conditions.

An intervention is usually considered appropriate for general use if its effectiveness has been demonstrated in at least one study reported in a peer-reviewed journal, and if this success has been replicated at least one time in another setting.

Regional centers are often asked by parents to purchase services for which there is little if any evidence of effectiveness. History provides numerous examples of services of unproven value that have been used to treat people with developmental disabilities. The most recent example of such an intervention is the Wild Game Diet, requiring the child with autism to be fed nothing but wild game. Parents' opinions about the appropriateness of a new or unproven intervention for their child may be

based on anecdotal evidence from other parents or unconfirmed claims of people who provide the intervention. Because parents are given the lead in creating their child's IPP and in determining which services are most likely to achieve the objectives in the plan, these opinions – no matter what their validity – can significantly influence what is purchased.

The Lanterman Act includes wording that gives regional centers apparent authority to use effectiveness as a criterion in purchasing services. For example, Section 4646 (a) mandates that the “provision of services to consumers and their families be effective in meeting the goals stated in the IPP...and reflect the cost-effective use of public resources.” Similarly, Section 4648 (a) (5) states that selection of a provider should consider the “provider’s ability to deliver quality services or supports which can accomplish all or part of the consumer’s individual program plan.”

Even if a regional center were to consider effectiveness as a criterion when purchasing a service, their decisions in this regard must withstand scrutiny in a fair hearing if parents choose to appeal. This requires regional centers to evaluate effectiveness of new or unproven interventions in a scientifically rigorous manner, a task that is beyond their capability.

There is a viable alternative to regional centers conducting such an evaluation. It is a model found in health care. Most health care organizations use a procedure called *technology assessment* to evaluate requests for new, experimental, or otherwise unproven interventions. (The word “technology” as used here applies primarily to clinical interventions.) Formal technology assessments are conducted by professionals who are recognized experts in the field. They include careful reviews of published studies, to the extent that they exist, as well as surveys of the opinions of experts in the particular clinical area.

Because technology assessment mechanisms are carefully designed to conform to principles of scientific rigor, and because they are based on the best professional opinions available, they are usually perceived as fair. Consequently, their decisions tend to be accepted both by consumers and by health care professionals. In addition, they are generally accepted as credible evidence in due process (appeals) hearings. A formal technology assessment process could be an effective way of balancing the frequently competing interests of effectiveness and parent choice.

To create an effective technology assessment function within a single regional center (and pay for it out of operations funds) would not be financially feasible. It would be feasible, however, to achieve this end on a statewide basis. DDS could establish a Technology Assessment Committee that regional centers, consumers and families, and fair hearing officers could use as the need arises. Such a process would have the added advantage of allowing decisions made at the request of one regional center to be disseminated to and used as a basis for decisions in other centers.

The California Legislature has established an excellent precedent for a state level independent review of technology. It is found in the Independent Medical Review process funded and maintained by the State Department of Managed Health Care. If a similar mechanism were established to evaluate new or unproven technologies in developmental services, the cost to the state would be more than offset by the dollars saved through the elimination of interventions that fail to demonstrate effectiveness. (See Recommendation 7.)

11. *Regional centers have limited capacity to determine objectively if a given service is necessary, appropriate, and effective in the individual case.*

The results of the type of scientific study described above reveal whether or not an intervention is effective when used in a controlled environment (e.g., with appropriate patients/clients being treated by specially trained providers following a strict protocol). An intervention that has been shown to be effective under such ideal circumstances may turn out to be ineffective when used in typical service settings, either because the service is not necessary or appropriate for the person receiving it or because the service provider lacks competence in the intervention.

Regional centers have ongoing responsibilities to address these two issues for all clients receiving services. With regard to the first question – Is the service necessary and appropriate in this case? – a center typically makes a decision based on a written assessment, in many cases completed by the service provider who will also provide the service if it is determined to be necessary and appropriate for the client. Rarely does an assessment conclude that the child does not need the intervention. Similarly, a decision about whether a service is leading to achievement of the stated objectives is made on the basis of a progress report submitted to the regional center by the same provider and reviewed by a regional center clinician.

Each type of situation possesses serious potential for conflict of interest, involving as it does a service provider making recommendations that have direct financial implications for him. The service provider may overstate the consumer's need for the service or the progress that has been made due to his desire to provide that service or in response to the wishes of family members who are hopeful, perhaps in the absence of evidence, that the service will help their child. Finally, there may be a genuine disagreement between the service provider and the regional center clinician about the necessity for the service or the appropriateness of continuing that service.

In a case where the regional center makes a decision not to authorize a service in the face of a recommendation to the contrary from the service provider, parents frequently initiate an appeal. The hearing officer's primary task, then, is to weigh one professional opinion (the regional center clinician) against another (the service provider). In practice, the emphasis in the Lanterman Act on honoring the wishes of the family frequently becomes the determining factor in the appeal.

One way to address this situation is to use independent assessors to evaluate necessity, appropriateness, and progress. In practice, centers have found it difficult to identify clinicians willing to restrict their practice to assessments since it is more financially advantageous for them to be involved in direct service provision. Using service providers to review one another's services also has not proven to be a viable option. Providers hesitate to make negative judgments about their colleagues' work.

The model of an independent arbiter, as exemplified by the Technology Assessment Committee described above, would seem appropriate for use by regional centers to address disagreements between their clinical staff and service providers. This strategy could be used to avoid fair hearings or it could be used as a part of the appeal process. The volume of such questions would be greater than the questions addressed through formal technology assessment, and would also be simpler to

answer. Consequently, it would be reasonable to organize regional committees (perhaps through local universities) for this purpose. (See Recommendation 8.)

- 12. The use of unallocated reductions as a cost-saving strategy during financial crises has proven to be a failed approach. It places the responsibility for reducing spending solely on individual regional centers rather than on the Legislature that could create an equitable policy framework with statewide application. At the same time, since all other policies stay in place in the face of unallocated reductions, regional centers have neither flexibility nor authority to enforce implementation of such a plan or to use other, more effective strategies for reducing spending.***

Regional centers have only the goodwill of their communities on which to rely when budget shortfalls make it necessary to implement expenditure plans. Although a powerful force, goodwill is not enough. In response to the current budget crisis, some families have stepped forward and expressed their willingness to reduce the level of services they receive or do whatever else is necessary to help the regional center through its crisis. Other families take the position that they will resist any attempts by the regional center to solve the problem by reducing services to their children, claiming that the Lanterman Act gives the state a responsibility to provide the services regardless of its financial situation.

The decision to use unallocated reductions as the strategy for controlling spending forces citizen boards, many of whom are themselves consumers and parents of consumers, to make ad hoc decisions in the absence of policy direction that should be forthcoming from the Legislature. Because the Legislature has failed to fulfill its proper role, regional center boards repeatedly shoulder the burden for solving a financial crisis that deserves a system-wide solution to ensure equity. They are placed in the untenable position of asking consumers or parents to reduce or forego services that they or their children need.

While requiring regional centers to work with their communities to develop plans for reducing spending, DDS retains the authority to reject such plans. Centers are left with a responsibility to reduce costs but no authority either to enforce the reductions or to use more effective strategies to reduce spending. As discussed earlier, expenditure plans proved to be unsuccessful in the budget crisis of the early '90s. Further, they lack fairness and equity because some regional center communities are able to rise to meet the challenge of reducing spending while others are not.

The state must provide regional centers with a realistic uniform policy framework that has statewide application. Given the current structure of the disabilities service system, it is only the state that has the capacity to establish statewide service standards and funding priorities, and hold regional centers and their communities accountable for their implementation. (See Recommendation 1 and 5.)

PART IV: RECOMMENDATIONS

A Note about the Recommendations

Many times in deliberations leading up to the development of this paper, concepts and techniques of managed health care emerged in the discussion and were perceived as having potential for addressing some of the challenges faced by the developmental services system. Consequently, some of the recommendations that follow are proposed as potentially useful if the state were to choose to adopt a managed approach to developmental services.

Systems for managing the delivery and financing of health services have evolved out of necessity. They are responses to the real and profound inadequacies in U.S. health care and a growing realization that the country can no longer support a health care system that allows virtually uncontrolled access to increasingly costly high-technology interventions at the expense of basic health care for everyone. Many of the strategies developed by managed care organizations to ensure more equitable distribution of finite health care dollars have been measurably effective in improving access and quality and reducing cost.

The parallels between health services and developmental services – in terms of the challenges they face – are clear. It is reasonable, therefore, to consider the application of management techniques developed for health care if they can be useful to ensure increased equity and accountability in the developmental services system. An overarching recommendation, then, is for DDS to carefully examine structures and strategies used by health care organizations to manage utilization, cost, and quality and determine their usefulness if applied to the regional center system.

Recommendations

The changes required by the first four recommendations that follow could be achieved by the end of the current fiscal year and implemented for FY 2003-04. The remaining recommendations would require a greater period to prepare for implementation.

Near-term Changes

Recommendation 1. Clearly specify the services included in the “benefit package” defined by the entitlement and develop uniform service standards and priorities so that these services are authorized equitably across regional centers.

Rationale. The entitlement described in the Lanterman Act is exceedingly broadly defined and the Act establishes no uniform standards or service priorities. Also, presently all services in an IPP are given equal weight because services are not prioritized based on, for example, health and safety concerns. The ambiguities in the language of the Act result in inequities in purchase of service spending within and between regional centers. They also result in an increased number of appeals and de-facto expansion of the entitlement by administrative law judges through their decisions. More specificity in the definition would ensure greater equity in regional center spending. Statewide standards would also ensure that people with similar needs would qualify for similar services no matter which regional center serves them. (See Issues 1, 2, 5, and 12.)

Recommendation 2. Reestablish the provision in the Lanterman Act regarding parental financial responsibility for their child with a developmental disability.

Rationale. Until the provision “sunset” in January 2003, the Lanterman Act required regional centers to “take into account, in identifying the consumer’s service needs, the family’s responsibility for providing similar services to a child without disabilities (Section 4791).” This provision was useful in that it acted to moderate purchase of service spending while appropriately recognizing a family’s responsibility for their child with developmental disabilities. (See Issue 3.)

Recommendation 3. Implement a strategy for reasonable cost sharing for families of minors based on their ability to pay.

Rationale. Currently, the only circumstance under which a family is required to share in the cost of services for a child with developmental disabilities is if that family member is under the age of 18 and lives in a community care facility. Virtually every other federal or state entitlement program has some requirement for cost sharing or means testing for income eligibility. Striking a balance may require consideration of parents’ responsibility in meeting the needs of their children with developmental disabilities according to their means. But any strategy that is implemented must ensure access to necessary services and not create a financial hardship for families. (See Issue 3.)

Recommendation 4. Give regional centers authority to develop criteria for vrending service providers within their service area, including advocating with the Center for Medicare and Medicaid Services to allow a more reasonable interpretation of their requirement for parent choice.

Rationale. Currently, regional centers have limited authority to withhold vendor status from a provider. Regulations generally establish only minimum standards to qualify for vrending, and once a service provider achieves vendor status, the regional center is generally obligated to use that provider if a family or consumer requests it. Further, the provision of federal financial participation regarding parent “choice” has been interpreted as requiring vrending of virtually any service provider if parents request it. (See Issue 6.)

Recommendation 5. Give regional centers the authority to develop and implement their own methods for negotiating rates with providers.

Regional centers are in the unusual position of having the role of purchaser but having little control over how much they pay for the services they purchase. The current rate system has resulted in reimbursement that, in some cases, is too low and, in other cases, is overly generous. Giving regional centers the authority to negotiate rates at the local level would result in increased equity across providers and cost savings in some services. (See Issues 6, 8, and 12.)

Longer Term Changes

Recommendation 6. Give regional centers authority to develop standards for service quality and use these standards to identify “preferred” providers.

Rationale. Regional centers have no authority to enlist providers in quality improvement activities. Some centers have worked with their communities to develop quality improvement and quality enhancement programs for selected services, but provider participation in these programs remains voluntary. The implementation of quality standards would give regional centers a measurable way

to identify "quality" service providers who should receive priority in the referral process. (See Issues 6, 7, and 9.)

Recommendation 7. Develop a statewide Technology Assessment Committee that can be used by regional centers, consumers and families, and fair hearing officers to assess the efficacy of new or unproven service modalities.

Rationale. Regional centers have no capacity to rigorously evaluate new service modalities to determine whether or not they should be purchased for consumers and families. If such evaluations were made, they would need to be perceived as fair by service providers and families and they would need to stand up to scrutiny in fair hearings. The technology assessment process as used in health care organizations is an appropriate model to achieve these ends. (See Issue 10.)

Recommendation 8. Support the development of regional peer review resources that could be used by regional centers, consumers and families, and fair hearing officers to solicit independent opinions on the necessity, appropriateness, or effectiveness of services in individual cases.

Rationale. Currently, if a regional center clinician makes a recommendation not to purchase or to discontinue the purchase of a service in an individual case, that decision is frequently challenged by the service provider or the family. If the disagreement results in a fair hearing, the hearing officer's primary task is to weigh one professional opinion (the regional center clinician) against another (the service provider). In practice, the emphasis in the Lanterman Act on honoring the wishes of the family frequently becomes the determining factor in such an appeal. A model of an independent professional arbiter would seem to be useful to address this problem, but regional centers find it difficult to find professionals among their network of service providers who are willing to play this role. (See Issue 11.)

Recommendation 9. Complete the process of "system reform" to achieve an equitable and cost-effective rate system based on performance and consumer outcomes.

Rationale. There exists in the developmental services system a significant number of potentially excellent providers whose reimbursement rates are too low to allow them to provide good quality services and ensure their survival. At the same time, rates for some other service providers are overly generous. Make it a priority to complete the system reform process that has been tabled and fund rate increases by keeping monies generated by waiver programs in the regional center system. (See Issue 8.)

Recommendation 10. Establish a system for administrative review of OAH decisions to ensure that they comply with the applicable laws.

Rationale. While the right of consumers and parents to appeal is unquestioned, there is no limit on the types of regional center decisions that are subject to appeal. Further, the broad definition of the entitlement and the ambiguity in the Lanterman Act encourages families to appeal regional center decisions and fair hearing officers to use broad discretion in interpreting the law. This results in de facto expansion of the entitlement. Other than an appeal in the Superior Court, there is no oversight system to ensure that OAH decisions are both fair to all parties and reflect a correct interpretation of relevant law and regulation. Further, the process of appealing in Superior Court is costly for regional centers and, often, for families. (See Issue 4.)